The PEG dilemma
Feeding tubes are not the answer in advanced dementia

Marissa Galicia-Castillo, MD

Dilemma: a) a problem involving a difficult choice; b) a difficult or persistent problem

...What is distressing or painful about a dilemma is having to make a choice one does not want to make.

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Approximately 4.5 million adults in the United States have a diagnosis of dementia today. With Baby Boomers aging, that number is expected to quadruple to 22 million in the next 50 years. For patients in the latter stages of dementia, feeding problems invariably arise. A dementia patient’s inability to feed him/herself poses both medical and ethical dilemmas not only for physicians but also for family members.

The article, “To PEG or not to PEG: A review of evidence for placing feeding tubes in advanced dementia and the decision-making process,” (pg. 30) reviews the issues and the misconceptions regarding the use of percutaneous endoscopic gastrostomy (PEG) tubes in this specific patient population. Because technology has made inserting a PEG “easy,” with minimal complications at the time of placement, PEG tubes naturally became the ‘answer’ to feeding problems in those who are cognitively impaired.

Many assumptions we physicians make regarding PEG tubes, however, are false. Specifically, there is no evidence to support that PEG tubes prevent aspiration, malnutrition, or pressure ulcer formation; PEG tubes do not improve functional status or quality of life.

What often happens is that there is a strong emotional response by the family that guides such decisions. No one wants to make the decision to ‘starve their family member to death.’ The best way to overcome this is through education. Patients and families need to be given information regarding what we currently know about the outcome of demented patients who receive PEG tubes.

Not only do patients and families need to be educated, but we physicians have to be better informed as well. In a recent study by Shega et al, primary care physicians reported that they believed that feeding tubes did prevent aspiration, improve pressure ulcer healing, survival, and nutritional status. One can imagine it would be quite difficult to dissuade the patient and family when the physician him/herself feels that such tubes are...
of benefit in this population. A clinically useful, ethically-based decision-making algorithm (see Figure), devised by Rabeneck et al, provides some guidelines for the placement of PEG tubes. Tools such as this can help practitioners in making decisions and talking with families.

Communicating with families is key: One study found that the information given regarding PEG tubes to families was incomplete: Adequate information was reported for method of placement (29%), potential complications (38%), and process of feeding (45%). Another study found that families reported incomplete information and "considerable distress" in making the decision, with decision-makers reporting that they perceived few alternatives.

Often, in my experience, once patients and families understand that PEG tubes do not accomplish what they thought they would, the decision is made not to place it. If the patient truly is no longer able to eat, this signifies that the patient is entering the final phase of illness. It is important to also offer palliative care to patients and their families. A hospice referral may be appropriate.

Recommending hand-feeding is always an option (See "Nutrition in advanced dementia: Tube-feeding or hand-feeding until death?" by Fredrick T. Sherman, MD, MSc, Geriatrics 2003; 58(Nov):10,12). There are financial considerations, however, since Medicaid reimburses at a higher rate for tube-feedings. While hand-feeding does offer benefits, it must be done properly and as such, can require 45 to 90 minutes a day per patient—clearly more time-intensive than the 15 to 30 minutes per day required for tube-feedings.

The ease of PEG tube placements combined with the increase in patients with dementia means the conversation about placing or not placing PEG tubes will become more prevalent. It is important for us as primary care practitioners to understand all evidence. At this point, there is no evidence that the placement of a PEG tube in a patient with advanced dementia offers any type of benefit.

It is also our job as primary care physicians to ensure that families and patients are well-informed not only about PEG tubes, but also about the natural course of dementia.

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**Figure Decision-making algorithm for PEG tube placement**

<table>
<thead>
<tr>
<th>Clinical category</th>
<th>Clinical guideline</th>
<th>Ethical rationale for guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia-cachexia syndrome?</td>
<td><strong>Yes ▶</strong> Do not offer PEG</td>
<td>Patient unable to make use of nutrients</td>
</tr>
<tr>
<td>Permanent vegetative state?</td>
<td><strong>Yes ▶</strong> Offer and recommend against PEG</td>
<td>Patient unable to experience any quality of life</td>
</tr>
<tr>
<td>Dysphagia without complications?</td>
<td><strong>Yes ▶</strong> Offer and recommend PEG</td>
<td>Patient unequivocally benefits from PEG</td>
</tr>
<tr>
<td>Dysphagia with complications?</td>
<td><strong>Yes ▶</strong> Discuss no PEG vs trial of PEG</td>
<td>Patient equivocally benefits from PEG and potential exists for loss of quality of life</td>
</tr>
</tbody>
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References


Send letters and comments to:
Fredrick T. Sherman, MD, MSc
Geriatrics
7500 Old Oak Blvd.
Cleveland, OH 44130
fsherman@advanstar.com